



Executive Summary

Excerpt from CSG's *State Official's Guide to Health Literacy*

Health care in the United States is in crisis. The return of double-digit health care inflation, the continued difficulties many have with affordability and access to basic health care and insurance, and alarming reports of widespread medical errors and other concerns with the quality of health care are just a few of the problems that confront state policymakers. These issues, combined with severe economic troubles at the state level, leave state leaders with few remedies for treating what ails the nation's health care system.

"The major obstacle to achieving a more informed and active health care consumer, however, is the lack of basic health literacy in the United States."

One approach widely promoted as a solution to problems with cost, access and quality is to encourage consumers to be more involved in health care decisions. In theory, a more informed and involved health care consumer would know where to find affordable health coverage, would be more cost-conscious, would know what questions to ask about a test or procedure and would feel empowered to prevent medical errors before they happen. An active consumer would act as a guardian of quality and affordable care in a way that state governments, insurance companies and other payers never could.

The major obstacle to achieving a more informed and active health care consumer, however, is the lack of basic health literacy in the United States.

The Council of State Governments is at the forefront in analyzing states' roles in improving low health literacy. Using data from its *National Survey on Health Literacy Initiatives*, CSG published the *State Official's Guide to Health Literacy*, an overview of how health literacy affects states and what they can do to address this issue. For more information about CSG's activities, please visit www.csg.org (keyword: Health Literacy).

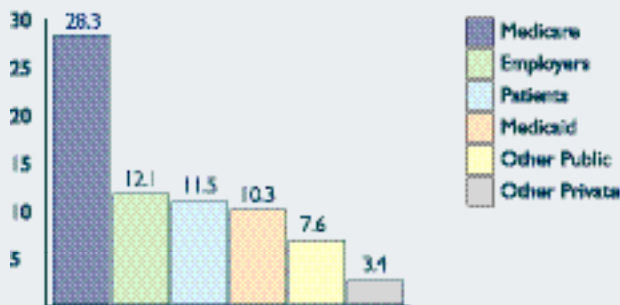


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The Council of State Governments would like to thank Pfizer, Inc., for its support in creating the Health Literacy Tool Kit.

Figure 1. The Cost of Low Health Literacy by Payee in 1998 Dollars



Source: "Low Health Literacy Skills Increase Annual Health Care Expenditures by \$73 Billion." www.agingociety.org/health/uhm.

Health literacy—the ability to read, understand and act on health information—is essential for anyone trying to navigate today’s complicated health care system. To be health literate, one must possess the reading, listening, reasoning and problem-solving skills necessary to make informed choices about health and health care.

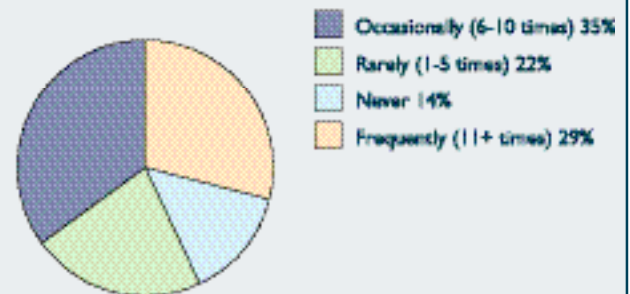
Research points overwhelmingly to the conclusion that large numbers of patients do not possess the necessary skills and knowledge to make sound health care decisions. The results of the 1992 National Adult Literacy Survey (NALS) indicate more than 46 percent of the adult population in the U.S. possess low or marginal literacy skills. Given the NALS findings and the complex and technical nature of health care, it is possible to conclude that more than half the population has difficulty understanding health care information due to inadequate health literacy. Consider also the following research findings:

- ◆ According to a study of patients at two public hospitals, 33 percent of English-speaking patients could not read basic health materials, 42 percent of patients did not know what “taking medication on an empty stomach” meant, 26 percent did not understand the information on an appointment slip, and 43 percent and 60 percent respectively could not understand the rights and responsibilities section of a Medicaid application or an informed consent document.¹
- ◆ A survey of Medicare managed care enrollees in four cities

found that more than a third of English-speaking and more than half of Spanish-speaking enrollees had inadequate or marginal health literacy. The study also found that reading skills decreased significantly with age.²

- ◆ Individuals with low health literacy who tested positive for HIV were four times more likely to be non-compliant with their medication.³
- ◆ Only 31 percent of patients with low literacy diagnosed with asthma understood that they needed to see their doctor even if they had not had an asthma attack, and only 45 percent knew that they must avoid the substances to which they are allergic, even when they were taking their medication as instructed.⁴
- ◆ A study published in the *Journal of the American Medical Association* found that of the 3,442 clinical decisions made during 1,057 encounters between a physician and a patient, only 9 percent met the criteria for informed consent.⁵
- ◆ A 1996 survey of 400 Medicaid managed care beneficiaries in New York found that more than 30 percent did not know managed care limited them to a specific network of providers; 60 percent did not know a referral was required to see a specialist; and 80 percent did not know use of the emergency room was limited.⁶

Figure 2. Number of times seen or heard the term “health literacy” as reported by governors’ offices, departments of public health, Medicaid/SCHIP offices



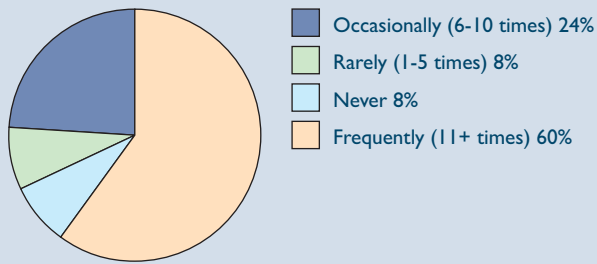
Source: Matthews, Trudi, and Sewell, Jenny. *State Officials' Guide to Health Literacy*. The Council of State Governments, 2002: 32.



Inadequate health literacy costs the U.S. health care system an estimated \$30–\$73 billion annually, according to a 1998 study done by the National Academy on an Aging Society.⁷ When broken down into expenditures by payer, this means that low health literacy costs Medicaid as much as \$10 billion annually—almost as much as Medicaid spent on prescription drugs and more than one-and-a-half times the amount it spent on physician services in 1998. (See Figure E-1 on the following page.)⁸

Many of the individuals who are most at risk of having low health literacy—seniors, low-income individuals and the chronically ill—are enrolled in public health care programs such as Medicaid, the State Children’s Health Insurance Program (SCHIP) and Medicare.

Figure 3. Number of times seen or heard the term “health literacy” as reported by departments of education and offices of adult literacy.



Source: Matthews, Trudi, and Sewell, Jenny. *State Official's Guide to Health Literacy*. The Council of State Governments, 2002: 32.

Because participants in these programs are also likely to be heavy users of health care services, it is especially important for state policy-makers to understand the barriers posed by low health literacy and to assess its impact at the state level.

If patients do not possess a basic knowledge of health and health care and the fundamental literacy skills necessary to actively participate in their care, they cannot be the informed and empowered consumers that the U.S. health care system needs if it is to achieve greater quality, efficiency, cost-effectiveness and access.

CSG's Survey of Health Literacy Efforts

To assist state policy-makers in addressing this problem, The Council of State Governments (CSG) undertook a major national research project. The goals of this project were to:

- ◆ Gather data from the latest research findings on health literacy.
- ◆ Determine what states are doing to make it easier for someone with low health literacy to navigate the health care system and efforts to improve health literacy.
- ◆ Prepare a report that provided the information and tools necessary for state leaders to determine what appropriate action they might take.

Early in 2002, with the assistance of a distinguished group of advisors, CSG prepared and sent its *National Survey on Health Literacy Initiatives* to governors' offices, departments of health, Medicaid and SCHIP offices, departments of education and

offices of adult literacy. The purpose of the survey was to determine state officials' awareness of health literacy as an issue and to identify the state laws, rules or programs that assist individuals with low health literacy.

Conclusions from CSG's research

The most important finding of CSG's survey is that health literacy is an emerging issue that few states have addressed specifically and directly. Thus, for public policymakers, health literacy is an issue ripe for leadership.

While no state is addressing health literacy in a comprehensive, multifaceted manner, individual agencies in a handful of states—including Georgia, Illinois, Massachusetts, and Virginia—have established programs, hired staff or created task forces to respond to low health literacy and its effects on health care delivery. From these states, as well as from several others, a number of notable approaches emerged from the survey responses:

- ◆ Virginia's Center for Primary Care and Rural Health established a Health Literacy Network to promote the use of plain language and to offer resources to health care providers, agency staff and others wanting to assist specific populations access care. In 1999, the Center sponsored a health literacy conference for national, state and local health care programs.
- ◆ The Illinois Secretary of State's Literacy Office created a Health Literacy Task Force to spearhead "Health Literacy For All," a program designed to aid parents in understanding health information.
- ◆ The state of Alaska produced "Healthy Reading Kits" for grades two through eight. The texts referenced in the kit have strong health content and the teacher's manual that accompanies the kit helps educators tie the books to Alaska's reading standards.
- ◆ California approved its *Health Framework for California's Public Schools, Kindergarten Through Grade Twelve*, a tool to aid health education curriculum development at the local level and to promote collaborations between schools, parents and the community.
- ◆ Massachusetts' medical assistance programs have been at the forefront of providing multilingual assistance, videos in multiple languages and training staff to convey health care information in a way that is easy to understand. Massachusetts also has an Adult Basic Education Health Curriculum Framework for adult literacy classes.
- ◆ Georgia's Department of Adult and Technical Information has hired a Health Literacy Coordinator to oversee the imple-





mentation of a series of health literacy classes throughout the state. Still in its early stages, this program has hosted classes in hospitals, senior centers, mental health facilities and community centers.

- ◆ Alabama's Medicaid agency has done extensive pilot testing of materials for enrollees. Through this work, the agency has learned that easy-to-read materials are preferred, even by those with proficient reading skills.

A number of states are also involved in activities that make it easier for someone with low health literacy to navigate public assistance programs—such as simplifying enrollment materials and procedures—or to increase health literacy by setting health education standards in both K–12 and adult literacy classes. Although these efforts have not been initiated or recognized to address the problem of low health literacy per se, they have been successful in removing barriers just the same.

CSG's State Official's Guide to Health Literacy

The *State Official's Guide to Health Literacy* provides an overview of research findings on the issue of health literacy and a summary of CSG's survey results. Chapter One defines health lit-

eracy and offers evidence as to why it matters to states. Chapter Two discusses various stakeholders involved in addressing low health literacy and provides information on resources and information available from a variety of organizations around the country. Chapter Three summarizes the findings from CSG's survey and highlights innovative programs and promising state approaches for dealing with low health literacy. Chapter Four offers state policy-makers a number of questions and data sources for determining the degree to which low health literacy affects their respective states.

Endnotes

¹Williams M., Parker R., Baker D., et al. "Inadequate functional health literacy among patients at two public hospitals." *JAMA*, December 6, 1995: v274 n21.

²Gazmararian, J., Baker, D., Williams, M., et al. "Health Literacy Among Medicare Enrollees in a Managed Care Organization." *JAMA*, February 10, 1999: v281 n6.

³Kalichman, S., Ramachandran, B., and Catz, S. "Adherence to Combination Antiretroviral Therapies in HIV Patients of Low Health Literacy." *Journal of General Internal Medicine*, May 1999: v14 n5.

⁴Williams, M., Baker, D., Honig, E., et al. "Inadequate Literacy Is a Barrier to Asthma Knowledge and Self-Care." *Chest*, 1998: v114 n4.

⁵Braddock, C., Edwards, K., Hasenberg, N., et al. "Informed Decision Making in Outpatient Practice." *JAMA*, December 22/29, 1999, v282 n24.

⁶Molnar, Christine. "The Next Steps in Fostering Consumer Participation in Medicaid and SCHIP Managed Care." *Journal of Ambulatory Care Management*: July 2001.

⁷"Low Health Literacy Skills Increase Annual health Care Expenditures by \$73 Billion." www.agingsociety.org/healthlit.htm.

⁸"Chart Book 2000: A Profile of Medicaid" Health Care Financing Administration.





New Tools for an Old Problem:

Overcoming Health Literacy Barriers in Medicaid

States all over the country are struggling to find innovative ways to control Medicaid costs. Unfortunately, few cost-containment options are available to state leaders that do not also affect Medicaid enrollees' access to care or the quality of their health care benefits.

Among the options states are considering that hold the promise to improve care while also controlling costs are efforts to improve health literacy. According to a 1998 study by the National Academy on an Aging Society, low health literacy costs Medicaid as much as \$10.3 billion (in 1998 dollars) annually,¹ almost as much as Medicaid spent on prescription drugs and more than 1 1/2 times the amount it spent on physician services in 1998.²

Given the current state fiscal crisis – and especially the explosive increase in Medicaid spending – it is important state officials recognize the role low health literacy plays in increasing health care costs and decreasing quality of care.

Medicaid Populations At Risk

Research conducted over the last 15 years clearly illustrates that low health literacy affects many of the populations served by Medicaid, including low-income individuals, the chronically ill, and seniors.

Low-Income Individuals

The 1992 National Adult Literacy Survey revealed that 43 percent of individuals with low literacy lived in poverty and 70 percent either had no job or only had a part-time job.³ As a program for low-income individuals, Medicaid is likely to have a disproportionate share of beneficiaries with low health literacy.

A 1995 study conducted at two public hospitals showed that, of the 2,659 low-income patients interviewed:

- ◆ 26 percent could not read their appointment card;
- ◆ nearly 50 percent were unable to determine if they qualified for free care after reading information provided by the hospital;

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California's Healthy Families and Medi-Cal Programs

A 1998 report by the Medi-Cal Policy Institute, *Opening Doors: Improving the Healthy Families/Medi-Cal Application Process*, offered several suggestions for simplifying the state's 28-page joint SCHIP/Medicaid application. Out of these recommendations came Health-e-App, an Internet-based application that can be used by both clients and agency staff.

The application offers several user-friendly features, including: automatic error checking, computation of income and deductions, real-time determination of eligibility, information on providers, the ability to pay premiums electronically, confirmation that an application was received and the ability to track its progress, and the ability to move from English to Spanish versions.

A pilot test of the application showed that Health-e-App was faster, resulted in few errors and lead to greater customer satisfaction.

For more information on Health-e-App, please visit www.healtheapp.org.

- ◆ 33 percent of English-speaking patients could not read basic health materials;
- ◆ 42 percent of patients did not know what "taking medication on an empty stomach" meant;
- ◆ 60 percent could not understand an informed-consent document.⁴

Chronically Ill

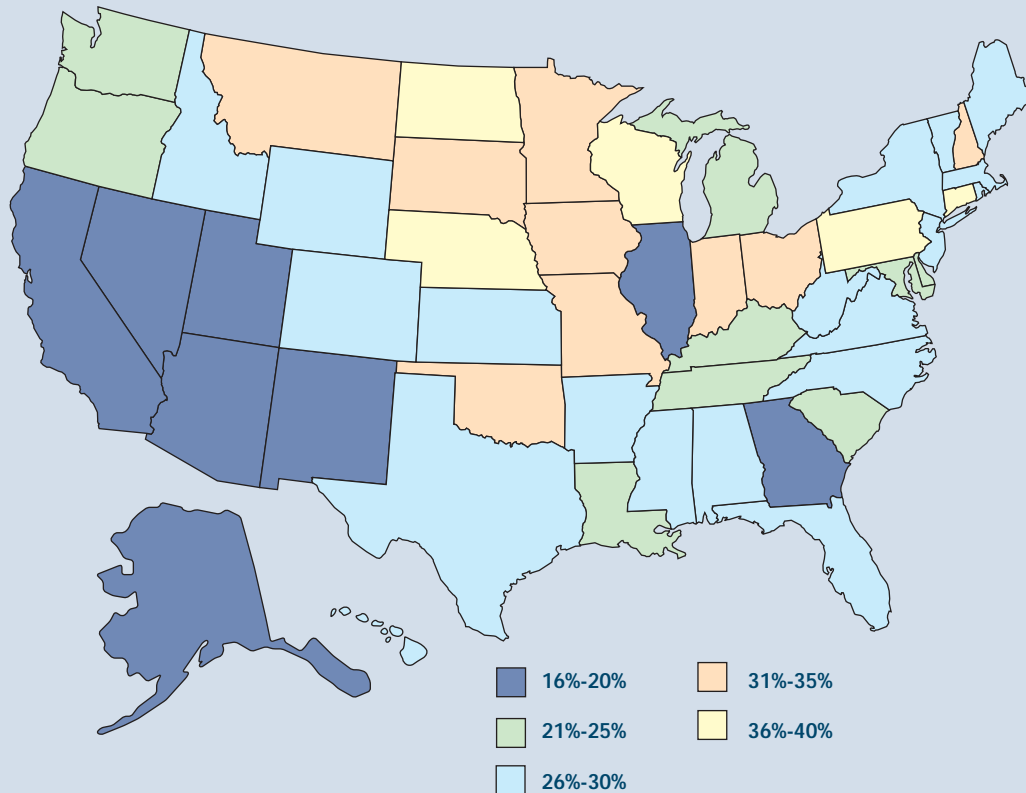
The National Adult Literacy Survey also revealed a sharp distinction in literacy skills among respondents who reported suffering from a prolonged illness: 75 percent had limited literacy skills.⁵ The ability to read and write inevitably has a significant effect on an individual's ability to manage his or her illness.

In 2000, an estimated 125 million Americans – less than half the population – suffered from at least one chronic illness, yet the chronically ill were responsible for more than 75 percent of health care spending.⁶

Among Medicaid beneficiaries, the proportion is even higher:

- ◆ Adult beneficiaries with chronic or disabling conditions account for 96 percent of the total amount Medicaid spends on nonelderly adults.

Figure 1. Elderly as a Percent of Total Medicaid Spending, FY 1998



Source: The Henry J. Kaiser Family Foundation State Health Facts, <http://statehealthfacts.kff.org>.

- ◆ Child beneficiaries with chronic or disabling conditions account for 76 percent of the total amount Medicaid spends on children.⁷

Dually Eligible Seniors

According to the Center for Health Care Strategies, Inc., more than two-thirds of U.S. adults age 60 or older have low or marginal literacy skills.⁸ While Medicare pays for a significant share of senior health care costs, states are responsible for covering a portion of the costs of treating low-income seniors who also qualify for Medicaid – the dually eligible.

Although the elderly make up only 10 percent of enrollees, they are responsible for 27 percent of Medicaid expenditures (Figure 1 provides information on per state spending).⁹ Given how costly this population is, health literacy among seniors is a significant concern for states.

State Response

State responses to Medicaid beneficiaries with low health literacy vary both in the extent of the response and the point of interaction. Most states have tried to simplify enrollment in and access to state health care programs, and some have partnered with health care professionals and private health plans to better serve clients with low health literacy. In addition, most states provide services for non-English-speaking beneficiaries.

Simplifying Enrollment and Access

Medicaid is a complicated program that is difficult for most people to navigate, but especially for those with low health literacy. Data

from CSG's *National Survey on Health Literacy Initiatives* show that most states recognize this difficulty and have made some effort to simplify the process for enrolling in and accessing care. Of the states and territories responding to the survey, 95.9 percent had either simplified the language on enrollment forms for health care programs or had simplified the forms' organization to make them more understandable. Most respondents – 85.7 percent – had done both.

“Simplified eligibility forms have resulted in substantial increases in applications that are correctly filled out. Use of easy-to-read materials that repeat key messages are also highly affective and result in beneficiaries understanding when and how to access care, including when to go to the emergency room,” noted a respondent from Alabama Medicaid.

Among strategies to help beneficiaries, survey respondents ranked one-on-one assistance as one the most effective methods for helping people understand enrollment and access procedures. Eighty-two per-

cent of respondents offered one-on-one assistance to clients enrolling in state health insurance programs and 71.4 percent offered assistance for clients who have problems accessing care. This assistance took many forms:

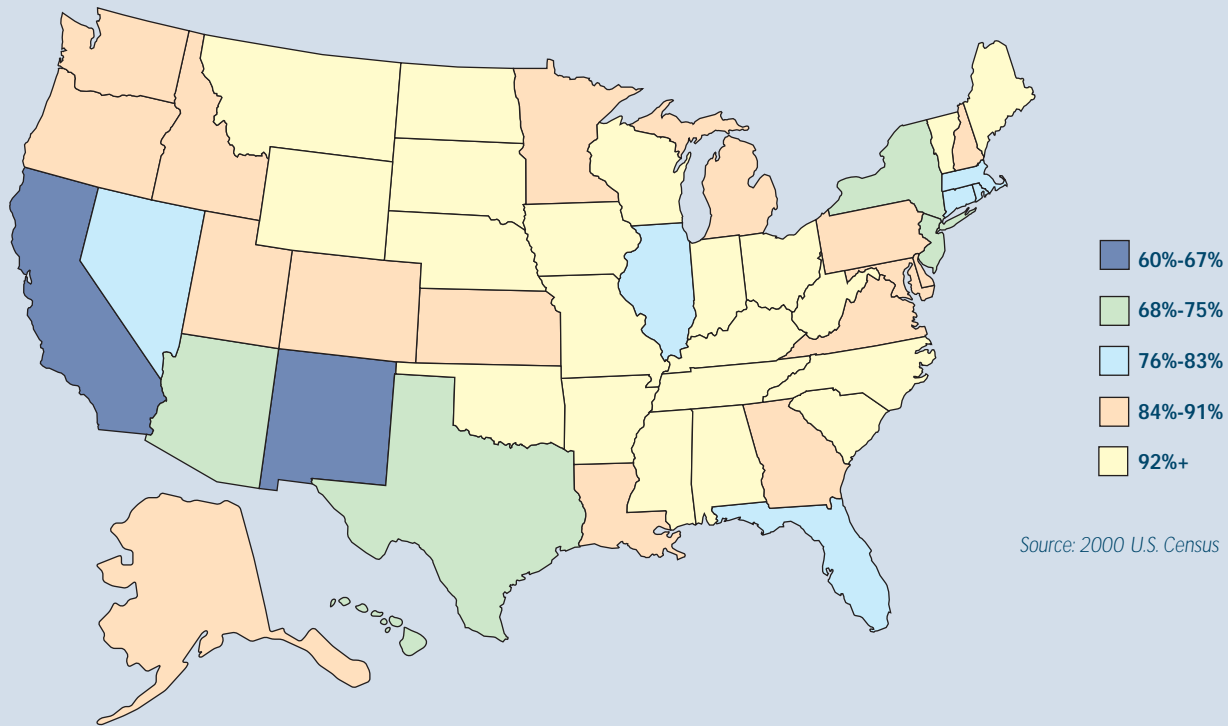
- ◆ 69.4 percent provided onsite assistance at state agency offices.
- ◆ 55.1 percent made assistance available through clinics.
- ◆ 67.3 percent of states reported that counseling was offered at local nonprofits or community centers.
- ◆ The vast majority of states – 83.7 percent – provided a toll-free number for individuals to call if they had questions.

Increased market penetration of Medicaid managed care over the last decade has increased the burden on beneficiaries with low health literacy. “Managed care – much more than fee-for-service system – creates an environment in which patients must take an active role in their own care, and, in fact, become discerning and vocal consumers.”¹⁰

To meet consumer demand for help with Medicaid managed care enrollment and access, the New York City Council created the Managed Care Consumer Assistance Program. Operated by the Community Service Society of New York (CSS), the program provides information and assistance through a network of 25 nonprofit organizations. One-on-one assistance is offered in English, Spanish, Chinese, Russian, Yiddish, Korean and Haitian-Creole. CSS has also put together *The Advocate's Guide to Managed Health Care*, which provides detailed information on Medicaid managed care, Medicare managed care, veterans' health benefits, and New York's Child Health Plus and Family Health Plus. (For more information, visit www.mccapny.org/.)

Staff at CSS have contributed to the research on successful patient education strategies in Medicaid managed care. In the report

Figure 2. Percent of Population, 5 Years and Older, Who Speak English at Home



“Educating Medicaid Beneficiaries About Managed Care: Approaches in 13 Cities,” the authors recommend that Medicaid programs should take the following steps to improve beneficiary education efforts:

- ◆ Materials should be tailored to the audience. Beneficiaries should have an opportunity to provide feedback about what information is included and how it is presented.
- ◆ Information should be up-to-date and provide specific information about each plan.
- ◆ Programs should assess materials’ effectiveness.
- ◆ Educating Medicaid managed care beneficiaries should be part of a larger, comprehensive initiative.¹¹

Accommodating Differences in Language and Culture

Patients who do not speak English or who have limited English-speaking abilities represent another vulnerable group within the Medicaid population at risk for low health literacy (Figure 2 provides information on percent of the population in each state who speaks English at home). According to CSG’s *National Survey on Health Literacy Initiatives*, most states provide one-on-one assistance in multiple languages. For some states, this means staffing agencies or “help lines” with people who speak other languages. Other states contract with an interpreter service, such as AT&T’s LanguageLine Services, to help health care providers and agency staff communicate with non-English-speaking clients.

Some states, such as Massachusetts, do both. Not only does Massachusetts have a dedicated customer service line staffed by multilingual employees, the state’s contract with AT&T provides clients with access to interpreters who collectively speak more than 140 languages. In addition, all materials for MassHealth (the state’s combined Medicaid and SCHIP program), including applications, are translated into English and Spanish. Certain materials are available in nine other languages: Arabic, Cambodian, Chinese, French, Haitian-Creole, Laotian, Portuguese, Russian and Vietnamese.

In many states, like New York, Medicaid managed care plans are

contractually required to provide information in a language if more than 5 percent of a county’s population speaks that language. This requirement is often specified in the terms and conditions of a state’s 1115 waiver.

Florida Health Literacy Study

In 2001, Florida’s Agency for Health Care Administration announced a partnership with Pfizer, Inc., to assist Medicaid recipients who suffer from four common chronic conditions: congestive heart failure, diabetes, asthma and hypertension. “Florida: A Health State” has three components: the Florida Health Literacy Study, hospital-based disease management, and expansion of Pfizer’s drug donation program.

The Florida Health Literacy Study, which is being conducted by the University of South Florida, will evaluate the effectiveness of a health education program titled “For Your Health” targeted to patients diagnosed with Type 2 diabetes and/or high blood pressure who have low health literacy. The program provides:

- ◆ training for selected Community Health Center providers and staff;
- ◆ educational materials that are designed for individuals with low literacy skills and that are culturally appropriate;
- ◆ classes and one-on-one sessions for patients participating in the study.

The program’s effectiveness will be evaluated based on an increase in patients’ knowledge of and control of their disease. The university will also examine the indirect impact of health literacy efforts, including cost savings and health outcomes.

Molina Healthcare of California

In March 2001, Molina Healthcare of California, a Medi-Cal provider, began a study to find out if improving parent confidence in responding to a child's non-urgent health problems decreased inappropriate emergency room visits.

Molina distributed 11,000 copies of the book *What To Do When Your Child Gets Sick* to its Medi-Cal members with children five years and younger. The book, written at a third- to fifth-grade reading level, is intended to be an easy-to-use reference with lots of illustrations. Unlike the health information often distributed by health plans, this book appeals even to members with low literacy, offering them a resource that will help them decide when they need to go to the emergency room and when they should wait and make an appointment with their primary provider.

Results from the first year of the study show a significant (6.7 percent) decline in ER use for treating fever and vomiting/diarrhea for those families that received a copy of the book. A survey of individuals who had been sent the book also showed a decline in the number choosing "go to the ER" when asked what they would do if their child had a fever or a rash.

Molina Healthcare of California Claims Data Analysis of ER Utilization

(Visit Rate per 1,000 members under six)



Source: "Health Literacy: An Overview and Research-Supported Solutions." Institute for Healthcare Advancement. www.ih4health.org/pdf/research_brochures.pdf.

Financing and Delivery of Care

Medicaid and SCHIP programs can also consider health literacy when making purchasing decisions and negotiating contracts with health plans and providers. For example, to ensure written materials are prepared at a level that is appropriate for beneficiaries, contracts can set specific readability requirements for enrollment forms, information on available benefits and how to access services, and documents that explain procedures for filing a complaint or grievance.

State health programs should consider the following characteristics when evaluating written materials:

- ◆ Language is targeted to the audience and written at an appropriate grade level.
- ◆ Illustrations are relevant.
- ◆ Pages are uncluttered with lots of white space.
- ◆ Fonts are large enough for the intended audience and consistent throughout the document.
- ◆ Text is culturally sensitive.
- ◆ The tone is friendly.

States can also work with vendors to identify populations who are at risk for low health literacy and create interventions that will educate clients about disease and encourage appropriate use of health care services

Conclusion

Research shows that low health literacy costs states a significant amount of money in their Medicaid programs. By taking steps

to address this issue, states are not only reducing the financial burden, they are also improving quality and access to care for beneficiaries.

— *This publication was prepared by Jenny Sewell, health policy analyst, for the Council of State Governments. For more information about health literacy at CSG, please contact her at (859) 244-8154 or jsewell@csg.org. The Council of State Governments would like to thank Pfizer, Inc., for its support in creating the Health Literacy Tool Kit.*

Endnotes

- ¹"Low Health Literacy Skills Increase Annual Health Care Expenditures by \$73 Billion." www.agingociety.org/agingociety/publications/fact/fact_low.html.
- ²"Chart Book 2000: A Profile of Medicaid." Health Care Financing Administration. www.cms.hhs.gov/charts/medicaid/2tchartbk.pdf.
- ³"Fact Sheet: Adult and Family Literacy April 2000." National Institute for Literacy. www.nifl.gov/nifl/policy/familitfactsheet.doc
- ⁴Williams, M., Parker, R., Baker, D., et al. "Inadequate Functional Health Literacy Among Patients at Two Public Hospitals." *JAMA*, 1995, v274n21: 1677-1682.
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- ⁷"The Faces of Medicaid." Center for Health Care Strategies, Inc. www.chcs.org/publications/pdf/cfm/Identify.pdf.
- ⁸"Who Has Health Literacy Problems?" Center for Health Care Strategies, Inc. www.chcs.org/resource/hl.html.
- ⁹"State Health Facts Online." Kaiser Family Foundation. www.statehealthfacts.kff.org/
- ¹⁰Molnar, Christine. "The Next Steps in Fostering Consumer Participation in Medicaid and S-CHIP Managed Care." *Journal of Ambulatory Care Management*: July 2001.
- ¹¹Kaplan, S., et al. "Educating Medicaid Beneficiaries About Managed Care: Approaches in 13 Cities." The Commonwealth Fund, May 2000.





Opportunities for Change:

Improving Health Communication

Improving health communication, whether written or oral, is an essential step in improving health literacy. Each interaction – between a patient and a provider, between a health plan and a member, or between public health departments or voluntary health associations and the community – is an opportunity to craft a message that is appropriate for the audience and gives individuals the information they need to make positive health decisions.

State decision-makers play an important role in improving health communication. Mandated policies and procedures affect the availability of one-on-one assistance for individuals, the grade level at which materials are prepared, and the availability of materials in languages other than English. State policy-makers also play a role in authorizing informational campaigns and increasing awareness of how low health literacy affects care.



Educating the Public

Government-sponsored public health campaigns are common tools in addressing health issues, such as diabetes, cancer, HIV/AIDS and obesity. Through these initiatives, the government is able to draw attention to risky behav-

Ask Me 3

This year, a coalition of leading health and civic organizations – including the American Medical Association, the American Nurses Association, National Council on Aging, and Partnership for Prevention – joined together to form the Partnership for Clear Communication. The coalition's goal is to promote awareness of and solutions to low health literacy and its effect on health outcomes by educating patients and providers; improving patient-provider communication; researching health literacy and evaluating solutions; and increasing support for health literacy policy and funding.

Ask Me 3 is a tool developed by the partnership to improve health communication between patients and providers. Materials available at www.askme3.org promote three simple questions patients can ask their providers in every health care interaction:

1. What is my main problem?
2. What do I need to do?
3. Why is it important for me to do this?

The information is aimed not only at consumers but also at public health officials, health care professionals, health educators, literacy specialists, patient advocates and caregivers, health associations and policy-makers. To learn more, visit www.askme3.org.

iors, appropriate responses, and available methods of treatment and prevention.

A mismatch, however, between the level at which the message is prepared and the health literacy level of the intended audience can undermine the effort's effectiveness. An article in the *Journal of the American Medical Association* noted that "numerous studies document that health materials, such as patient education brochures, discharge instructions, contraception instructions, and consent forms are often written at levels exceeding patients' reading skills. The problem is magnified by the increasing multicultural and multilingual diversity of the U.S. population."¹

To overcome this disconnect, efforts to educate patients and the community should be appropriate even for individuals with low literacy skills. This can be accomplished in a number of ways but probably the best way is to get feedback from the intended audience. Pilot-testing materials offers states an opportunity to learn what works and what doesn't when communicating complex

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information to individuals with low health literacy. Readability tests that evaluate the grade level at which a message is prepared are also valuable tools.

Building Awareness

When planning a response to low health literacy, states can benefit from building awareness of the problem, especially among health care professionals, providers and health plans. Issues to address include:

- ◆ complicated enrollment and access procedures;
- ◆ use of medical jargon;
- ◆ ways to make consent forms easier to understand;
- ◆ hospital discharge instructions;
- ◆ prescription drug information and availability of pharmacists to answer questions;
- ◆ design and effectiveness of disease management programs; and
- ◆ patient education.

One researcher who works with adult learners recommends that health communication should provide a “safe environment to learn about health, the opportunity to ask questions and to consider the relevance of the information to everyday life, and the opportunity to talk about different cultural perceptions about health and medical treatment.”²

Within the medical community, there has been increased pressure to address issues of patient/provider communication (see sidebar on the American Medical Association). Recent research shows that many patients leave their doctor’s office not sure what was said or what they should do. A study published in *JAMA* evaluated 1,057 doctor-patient visits to determine if decisions made by the patient during the interaction qualified as “informed” using predetermined criteria. The study found that of the 3,442 clinical decisions made

during the visits, only 9 percent met the criteria. “Among the elements of informed decision making, discussion of the nature of the intervention occurred most frequently (71 percent) and assessment of patient understanding least frequently (1.5 percent).”³

State Response

Many state officials recognize that individuals who understand health information and who are able to make positive choices for themselves and their families will inevitably be more productive and will have better health outcomes. Some states have taken steps to encourage programs and initiatives to improve health communication and address low health literacy; examples of these are highlighted below.

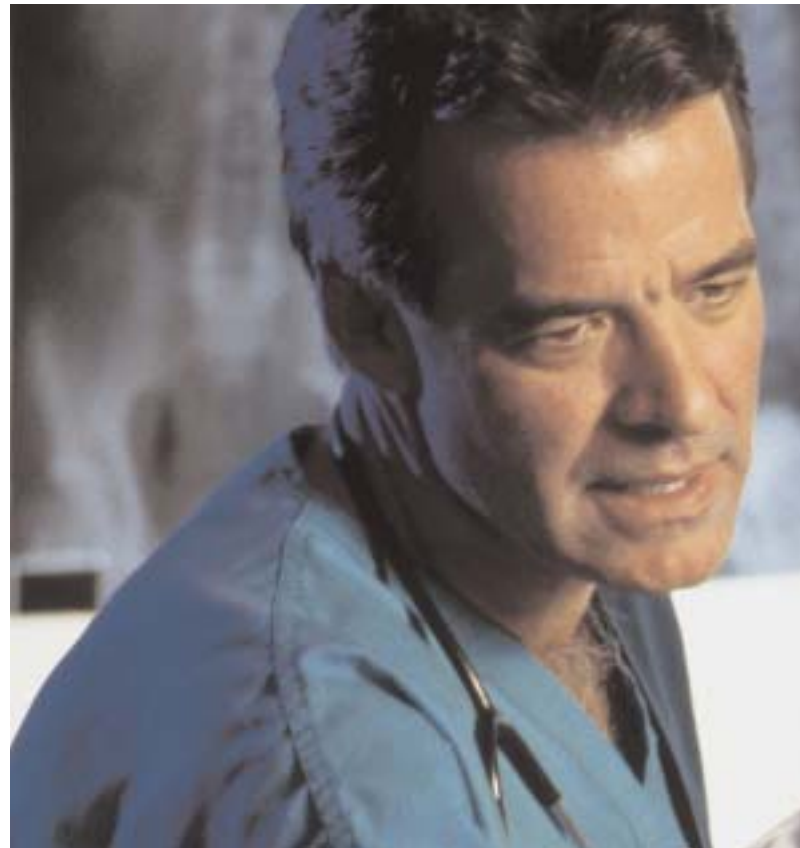
Louisiana

In order to evaluate how low health literacy affects the state, in 2003, the Louisiana Legislature passed a bill to create the Interagency Task Force on Health Literacy. According to HB 2019, the task force will be chaired by a faculty member of the Louisiana State University Health Sciences Center in Shreveport, an institution that has conducted some of the premier research in the field of health literacy.

Members of the task force will include individuals from a number of health-related agencies and organizations, such as the Louisiana State Medical Society, the Governor’s Office of Elderly Affairs, and the Louisiana Minority Health Commission. Representatives from the health insurance industry and area health education centers will also participate.

The task force is charged with:

- ◆ examining how low health literacy affects access to care and use of services;
- ◆ identifying groups at risk for low health literacy; and



- ◆ determining if providing appropriate health information and improving overall health literacy would increase efficiency and decrease expenditures.

Based on this examination, the task force will present recommendations to the Legislature by December 15, 2005.

Maryland

According to a recent report by the Institute of Medicine, *Unequal Treatment: What Healthcare Providers Need to Know About Racial and Ethnic Disparities in Healthcare*, even when factors such as level of insurance and ability to pay are considered, racial and ethnic minorities receive lower quality care than whites.

In response, Maryland passed HB 883, the Health Care Services Disparities Prevention Act. This legislation encourages state colleges and universities that train health care professionals to offer classes that increase awareness of the issue, including the role of health literacy. The bill also urges courses or seminars for those individuals who are required to participate in continuing education to maintain licensure.

“Good communication is essential,” said Delegate Shirley Nathan-Pulliam, lead sponsor of the bill. “When people understand how to take their medication, for example, or what their diagnosis is, they are able to take better care of themselves. From this comes improved health outcomes.”

The bill requires the Maryland Department of Health and Mental Hygiene to submit a report that, among other things, will give health care providers that participate in state-funded programs guidelines for cultural competency, sensitivity, and health literacy based on clients’ race, income, gender and ethnicity.

Alabama

When preparing materials for Alabama’s Medicaid population, agency employees learned that pilot-testing materials offers a won-

derful opportunity to learn what works and what doesn’t when communicating complex information to individuals with low health literacy. Extensive tests by Alabama’s Medicaid Agency revealed that:

- ◆ Even people with more advanced reading skills preferred easy-to-read materials.
- ◆ In addition to written materials, audio-visual materials must also be evaluated for accessibility. However, audiotapes and videos that complement written materials can lead to increased understanding.
- ◆ Efforts to educate beneficiaries allow doctors to focus on health care and not on the logistics of seeking care, ultimately strengthening the patient/provider relationship.
- ◆ Improving the layout of materials leads to greater utilization and retention of information.
- ◆ Materials translated into other languages are most effective when the dialect and cultural preferences of the audience are taken into consideration. Because individuals may be illiterate in their native language as well, use of artwork and other visuals is important.

AMA’s Health Literacy Toolkit

In June of 2000, the American Medical Association Foundation announced a multiyear program to address the issue of health literacy. The project’s aim is to help doctors better understand the problems caused by low health literacy and to provide information on improving doctor-patient communication.

As part of the initiative, the AMA Foundation created an education program for doctors and their staff titled “Health Literacy: Help Your Patients Understand.” The kit includes a manual, a documentary video showing individuals with low health literacy discussing how it affects them, handouts, information for patients, and buttons for office staff that read “Ask me, I can help.” Continuing education credit is offered for those who complete an evaluation.

Also as part of the initiative, the AMA Foundation is offering grants and awards to innovative health literacy educational and awareness programs. Recipients in 2003 include:

- ◆ *South Carolina Diabetes Prevention and Control Program.* The program will evaluate an educational video for adults with low literacy about the importance of diet and exercise in managing diabetes.
- ◆ *Arthritis Foundation and University of Mississippi Medical Center.* Grant money will cover the costs of developing and distributing a brochure about rheumatoid arthritis that can be comprehended on all literacy levels.
- ◆ *Iowa Department of Public Health.* Funding will help raise awareness of health literacy among low-income women who receive services from community-based Title V agencies.

For more information, visit the AMA Foundation Web site at www.amafoundation.org/go/healthliteracy.



“By using culturally appropriate, medically accurate photographs and artwork, we can enhance patient compliance. For example, organs are shown in the context of the entire body to facilitate understanding,” said Robin Rawls, associate director of research and development for the Alabama Medicaid Agency. “Artwork that illustrates the desired behavior is important because, even if the words are not understood, the photographs convey the correct message.”

Conclusion

Improving patient-provider communication is key to overcoming the problems caused by low health literacy. Efforts that lead to improved health communication, such as building awareness among health care providers and making the grade level at which oral and written communications occur more appropriate to the audience’s abilities, are important first steps. Many states have already taken the initiative, as have organizations such as the AMA. By championing these programs, state leaders can make a difference.

— *This publication was prepared by Jenny Sewell, health policy analyst, for the Council of State Governments. For more information about health literacy at CSG, please contact her at (859) 244-8154 or jsewell@csg.org. The Council of State Governments would like to thank Pfizer, Inc., for its support in creating the Health Literacy Tool Kit.*

Endnotes

¹“Health Literacy: Report on the Council on Scientific Affairs.” JAMA, February 10, 1999: v281 n6.

²Hohn, Marcia Drew. “Literacy, Health, and Health Literacy: State Policy Considerations.” Focus on Basics. World Education. February 2002, v5 nC, 20-25.

³Braddock, C., Edwards, K., Hasenberg, N., Laidley, T., and Levinson, W. “Informed Decision Making in Outpatient Practice.” JAMA, December 22/29, 1999, v282 n24.



TOFHLA and REALM: Evaluating Health Literacy

In evaluating patient health literacy, two tests are used most often – the Test of Functional Health Literacy in Adults (TOFHLA) and the Rapid Estimate of Adult Literacy in Medicine (REALM).

The TOFHLA, which is available in English and Spanish, uses real health materials to evaluate reading comprehension and numeracy. The test has 50 questions and takes about 20 minutes to administer. A short version is also available that takes around seven minutes to administer. The REALM evaluates word recognition and pronunciation. Based on performance, the patient is placed in one of four categories that correspond to a grade level. The REALM takes about five minutes to administer.

The tests are usually administered in a research setting, although they can be used in primary practice. However, Dr. Rima Rudd, a principal investigator with the National Center for the Study of Adult Learning and Literacy and a lecturer at the Harvard School of Public Health, cautions against using the test in doctors’ offices for two reasons. First, everyone – even people with excellent literacy skills – prefers plain language. Second, for individuals with poor literacy skills, having to take a test when they go to see their doctor may make them less likely to seek help or leave them feeling ashamed.

Sources:

Kiefer, Kristen. “Health Literacy: Responding to the Need for Help.” Center for Medicare Education, February 2001. www.medicareed.org/cmepublications.html
“Talking the Talk: Improving Patient-Provider Communication.” Facts of Life. Center for the Advancement of Health. March 2003, v8 n3, www.cfah.org/factsoflife/vol8no3.cfm.





Kids are the Key:

Elementary and Secondary Health Literacy Education

While solutions to low health literacy often target adult populations, primary and secondary schools should not be overlooked as important partners in addressing this issue. According to the federal government's public health agenda, *Healthy People 2010*, "Schools have more influence on the lives of young people than any other social institution except the family and provide a setting in which friendship networks develop, socialization occurs, and norms that govern behavior are developed and reinforced."¹ In recognition of the role schools play, academics, state and federal government, and other organizations are working to transform health education into *health literacy* education.

Study after study shows health education improves students' overall health knowledge and decreases the likelihood that students will adopt risky behaviors. Health education is especially important considering rising health care costs. A recent report from the Forum on Child and Family Statistics, *America's Children: Key National Indicators of Well-Being, 2003*, shows childhood obesity is increasing dramatically: from only 6 percent of children ages 6 to 18 in 1976-1980 to 15 percent in 1999-2000.² This has tremendous implications for future incidence of diabetes, heart disease, and cancer, and points to a sustained need for health and physical education.

Promoting Health Literacy in Schools

In 1995, the Joint Committee for National School Health Standards formed to develop a framework to guide health education curriculum development. Sponsored by the American Cancer Society, the committee was comprised of representatives from the Association for the Advancement of Health Education; the American Public Health Association; the American School Health Association; and the Society of State Directors of Health, Physical Education and Recreation. It recommended the following seven broad standards to promote health literacy, outlining performance objectives for each standard:

The Council of State Governments is at the forefront in analyzing states' roles in improving low health literacy. Using data from its *National Survey on Health Literacy Initiatives*, CSG published the *State Official's Guide to Health Literacy*, an overview of how health literacy affects states and what they can do to address this issue. For more information about CSG's activities, please visit www.csg.org (keyword: Health Literacy).



Selected State Links

- ◆ Alaska: *Skills for a Healthy Life Framework*, www.educ.state.ak.us/tls/frameworks/health/1table.htm.
- ◆ California: *Health Framework for California Public Schools Kindergarten Through Grade 12*, www.cdem.ca.gov/cfir/health/.
- ◆ Massachusetts: *Comprehensive Health Curriculum Framework for K-12*, www.doe.mass.edu/frameworks/health99/toc.html.
- ◆ Missouri: *Frameworks for Curriculum Development Health/Physical Education*, www.dese.state.mo.us/divimprove/curriculum/frameworks/over3.html.
- ◆ New Jersey: *Comprehensive Health Education and Physical Education Curriculum Framework*, www.state.nj.us/njded/frameworks/chpe/.
- ◆ Rhode Island: *Health Literacy For All Children: The Rhode Island Health Education Framework*, www.ridoe.net/standards/frameworks/health/.

- ◆ **Standard One:** Understand basic health promotion and disease prevention concepts.
- ◆ **Standard Two:** Be able to access health information as well as products and services that promote health.
- ◆ **Standard Three:** Be able to act on health information to reduce health risks.
- ◆ **Standard Four:** Critically analyze how culture, media, technology and other factors affect health.
- ◆ **Standard Five:** Use communication skills to reduce health risks.
- ◆ **Standard Six:** Set goals and make decisions to reduce health risks.
- ◆ **Standard Seven:** Argue on behalf of personal, family and community health.³

Two years later, in 1997, the Institute of Medicine published *Schools and Health: Our Nation's Investment*. This report recommended that, given the research connecting early health and physical education with later behavior, age-appropriate health education should be taught every year during elementary and middle school. The report also recommended that, in high school, a one-semester health education course be made mandatory for graduation. Recognizing that pressures to meet performance standards may affect the amount of time a school is willing to devote to health education, the report suggested that schools should use

Figure 1. States Requiring Newly Hired Health Education Teachers to Have Undergraduate or Graduate Training in Health Education

Legend:

- Elementary Only
- Elementary, Middle/Junior High, and Senior High
- Senior High Only
- Middle/Junior High and Senior High Only
- No Requirement
- Incomplete Data

Source: School Health Policies and Programs Study, 2000. Centers for Disease Control and Prevention, www.cdc.gov/nccdphp/dash/shpps/.

Rhode Island

Rhode Island is one of 20 states that receive funding from the Centers for Disease Control and Prevention (CDC) to establish a state-wide program for coordinated school health. Rhode Island's plan for comprehensive school health, *Healthy*

State Response – Curriculum Standards

California

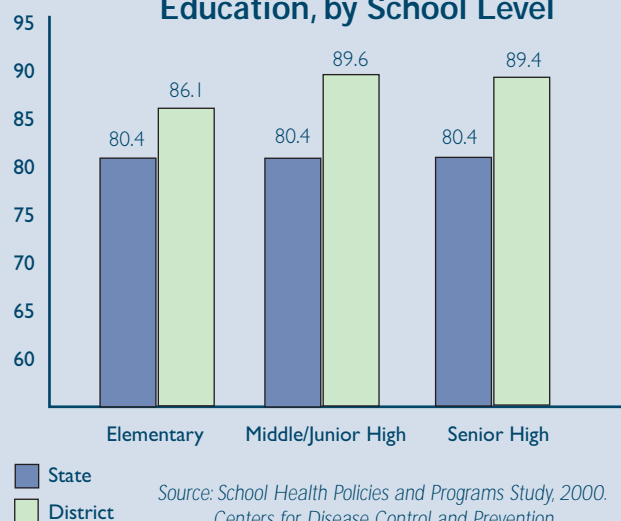
The framework was designed around four themes:

- Schools! Healthy Kids!*, includes the eight components outlined by the CDC:

- To assist local districts in implementation, the plan recommends state agencies strengthen the state-level infrastructure. The report identifies four areas states should address: policy, authorization and funding; personnel and organizational placement; resources; and communications.

According to a respondent to The Council of State Governments' 2002 *National Survey on Health Literacy Initiatives*, "Having a framework around which to center all health education efforts is a strength. Out of it grows curriculum and instructional changes, and it supports state-wide health education assessments."

Figure 2. Percentage of States and Districts Requiring Schools to Teach Health Education, by School Level



Source: School Health Policies and Programs Study, 2000. Centers for Disease Control and Prevention, www.cdc.gov/nccdphp/dash/shpps/.

explaining the importance of the goal, what the student should know, what skills the student should have, and offering sample student activities.

State Response – Teacher Education Requirements

According to the National Center for Education Statistics, most public school health education teachers have received some instruction in their subject area. In fact, middle and high school physical/health education teachers ranked second only to art and music teachers in an evaluation of teachers who had a major and a certification in the subject taught.⁶ (Figure 1 provides information on state training requirements).

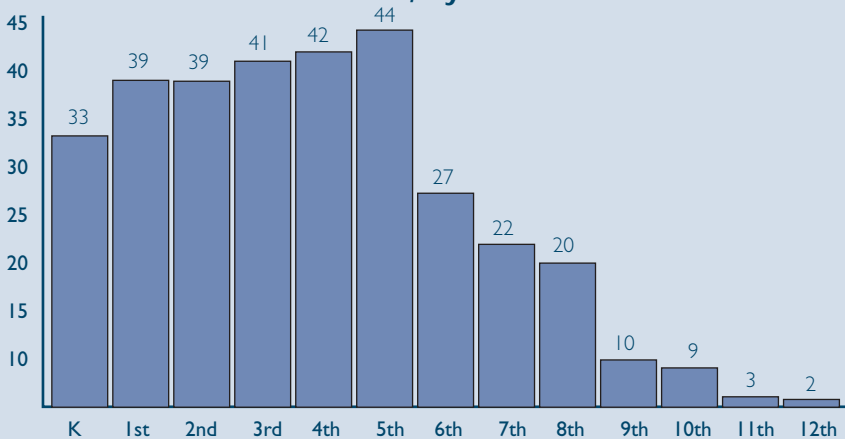
Even so, many states offer ongoing training for health teachers and other teachers who want to learn how to better integrate health information into the classroom. New Mexico is now in its third year of conducting the School Health Education Institute, a two-day training sponsored by the New Mexico Departments of Health and Education. The workshop is designed for high school educators who are asked to teach health topics in conjunction with their primary academic responsibilities. Experts in the field provide current, research-based information in an interactive workshop format. The institute focuses on five areas: physical activity; school safety; nutrition; tobacco, alcohol and other drug use prevention; and sexuality and HIV education.

New Jersey

The goal of New Jersey's Comprehensive Health Education and Physical Education Curriculum Framework is to outline a program that results in students who are both health literate and knowledgeable about physical fitness. This is important not only for the benefit to the student but to the community as a whole.

The state's standards stress that classes should be student-centered, with instructors adopting an interactive teaching style that encourages discussion. During classes, students should "discuss issues that have real application to their lives with assessments that are authentic and contextual. Teachers, well-versed in current health issues and resources, challenge students to take responsibility for their own health."⁵ New Jersey's standards outline program implementation, assessment strategies, and professional development requirements. They also provide sample learning activities.

Figure 3. Percentage of Schools that Require Health Education, By Grade



Source: School Health Policies and Programs Study, 2000. Centers for Disease Control and Prevention, www.cdc.gov/nccdphp/dash/shpps/.

Missouri

Missouri's 1993 Outstanding Schools Act outlined the state's "Show-Me Standards" – principles describing what public school students should know when they graduate. The act included seven health and physical education standards:

- ◆ Knowledge of human physiology.
- ◆ Principles of good physical and mental health.
- ◆ Knowledge of disease prevention, treatment and control.
- ◆ Principles of maintaining good physical fitness.
- ◆ Awareness of health risks and how to reduce them.
- ◆ Awareness of consumer health issues.
- ◆ Knowledge of emergency response.

The *Framework for Curriculum Development in Health Education and Physical Education (Healthy, Active Living)* that accompanies these standards provides guidance at the local level,

For the first time, this fall, New Mexico will offer a version of the training for elementary teachers, titled "Health is Elementary, a School Health Education Institute." The topics will be the same, and emphasis will be placed on integrating health information in the classroom. The goals of both institutes are that participants will:

- ◆ Gain knowledge, skills and an increased capacity to integrate health topics into other curricular areas.
- ◆ Receive current information and materials specific to the health-related topics they are being asked to teach.
- ◆ Discuss and plan with other teaching professionals to determine integration strategies.
- ◆ Network with health professionals who can provide technical assistance throughout the school year.
- ◆ Gain knowledge and skills that will help students meet or

succeed the required benchmarks and content standards for health and physical education.

Another state, Maine, provides a year-long professional development program on Comprehensive School Health Education. According to a representative from the Maine Department of Education, the various trainings and institutes offered to Maine's educators encourage enthusiasm about health education among teachers and the inclusion of health information in the classroom.

Assessment

While most schools are required either at the state or district level to teach health education, evaluating the effectiveness of state initiatives is difficult. Because curriculum decisions are often made at the local level, the content of health education classes, the grades in which it is taught and even the expected outcomes of the classes vary significantly. Information available from the CDC's School Health Policies and Programs Study indicates that while most schools require health education (Figure 2), it isn't necessarily taught every year throughout a student's academic career (Figure 3).

To assist states in assessing knowledge, the Council of Chief State School Officers, with funding from member states and the CDC's Division of Adolescent School Health, has been working since 1993 to provide comprehensive assessment tools to educators at all grade levels. Through its work, the Council hopes to improve states' ability to standardize curriculum, instruction and assessment of students, thus improving student health literacy.

Public/Private Sector Collaboration

Nonprofit and private sector organizations have long partnered with schools to improve students' health and to increase awareness of disease, healthy eating, and ways to avoid risky behavior. Among the benefits gained from partnering with outside organization are low- or no-cost health education resources, knowledgeable guest speakers, and fun educational field trips and activities.

Funding

Given the current state fiscal crisis, continued funding for health education programs is in jeopardy. The statewide assessment component of the Missouri program described above, for example, has been put on hold because of budget shortfalls. A contact at the Missouri Department of Elementary and Secondary Education said this was regrettable but not surprising. "The assessment helped districts focus what they taught and was really making a difference. Hopefully, it will be reinstated when more money becomes available."

The Council of State Governments' *National Survey on Health Literacy Initiatives* revealed that lack of funding for health education is a problem for many states that want to make health education a pri-

Additional Resources

- ◆ American Association for Health Education, www.aahperd.org/aahe.
- ◆ Council of Chief State School Officers, Health Education Assessment Project, www.ccsso.org.
- ◆ Division of Adolescent and School Health, Centers for Disease Control and Prevention, www.cdc.gov/nccdphp/dash/index.htm.
- ◆ School Health Policies and Program Studies, Centers for Disease Control and Prevention, www.cdc.gov/nccdphp/dash/shpps/.
- ◆ Schools and Health: Our Nation's Investment. Institute of Medicine, www.nap.edu/books/0309054354/html/.

ority. One respondent noted that, without financial support, "there is inconsistent quality of, and attention to, health education among local districts."

Conclusion

With a greater appreciation of health education and its role in establishing life-long patterns of behavior comes greater pressure to view it as a core component of any curriculum. Across the country, states have implemented standards to guide local school districts in designing and implementing effective health education classes. Health literacy often plays an important role in these curricula, especially as more policy-makers recognize the value of a health literate society. Out of these efforts, health literacy advocates hope today's students will gain the skills necessary to navigate the health care system of tomorrow.

— *This publication was prepared by Jenny Sewell, health policy analyst, for the Council of State Governments. For more information about health literacy at CSG, please contact her at (859) 244-8154 or jsewell@csg.org. The Council of State Governments would like to thank Pfizer, Inc., for its support in creating the Health Literacy Tool Kit.*

Endnotes

- ¹"Chapter 7: Educational and Community-Based Programs." *Healthy People 2010*. www.healthypeople.gov.
- ²*America's Children: Key National Indicators of Well-Being*. Forum on Child and Family Statistics, 2003. www.childstats.gov/americaschildren/.
- ³Summerfield, Liane. "National Standards for School Health Education" ERIC Clearinghouse on Teaching and Teacher Education, 1995. www.ed.gov/databases/ERIC_Digests/ed387483.html.
- ⁴*Health Framework for California Public Schools Kindergarten Through Grade Twelve*, www.cde.ca.gov/cdepress/health-frame.pdf.
- ⁵*New Jersey Core Curriculum Content Standards for Comprehensive Health and Physical Education*, www.state.nj.us/njded/cccs/drafts/chpe.pdf.
- ⁶"Qualifications of the Public School Teacher Workforce: Prevalence of Out-of-Field Teaching 1987–88 to 1999–2000," National Center for Education Statistics. http://nce.ed.gov/pubs/2003/quarterly/fall/2_2.asp.

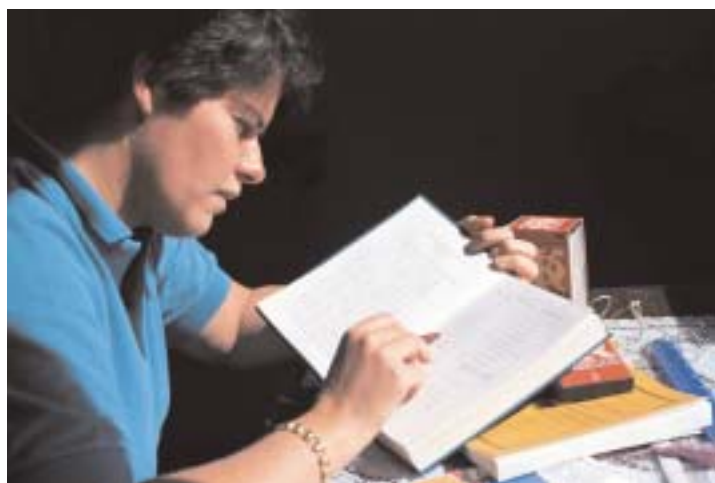




Teaching Health Literacy:

Adult Education Initiatives

In early 2000, Georgia started developing a unique program designed to use health information to increase literacy skills among its citizens. The program – known as the Health Literacy Pilot Project – was initiated under the leadership of Dr. Jean DeVard-Kemp, Assistant Commissioner of the Department of



Technical and Adult Education and head of the Office of Adult Literacy, who recognized that this was the direction in which Georgia needed to go. Responsibility for developing the project was given to Kim Lee, the director of assessment, evaluation, and GED administrator.

“It occurred to me that the population served by adult literacy programs would be the same population affected by low health literacy,” Lee said. “Using health materials to teach literacy skills, we could make a difference that would be beneficial for both the health care community and adult education.”

The Council of State Governments is at the forefront in analyzing states' roles in improving low health literacy. Using data from its *National Survey on Health Literacy Initiatives*, CSG published the *State Official's Guide to Health Literacy*, an overview of how health literacy affects states and what they can do to address this issue. For more information about CSG's activities, please visit www.csg.org (keyword: Health Literacy).



Why Is Teaching Health to Adult Learners Important?

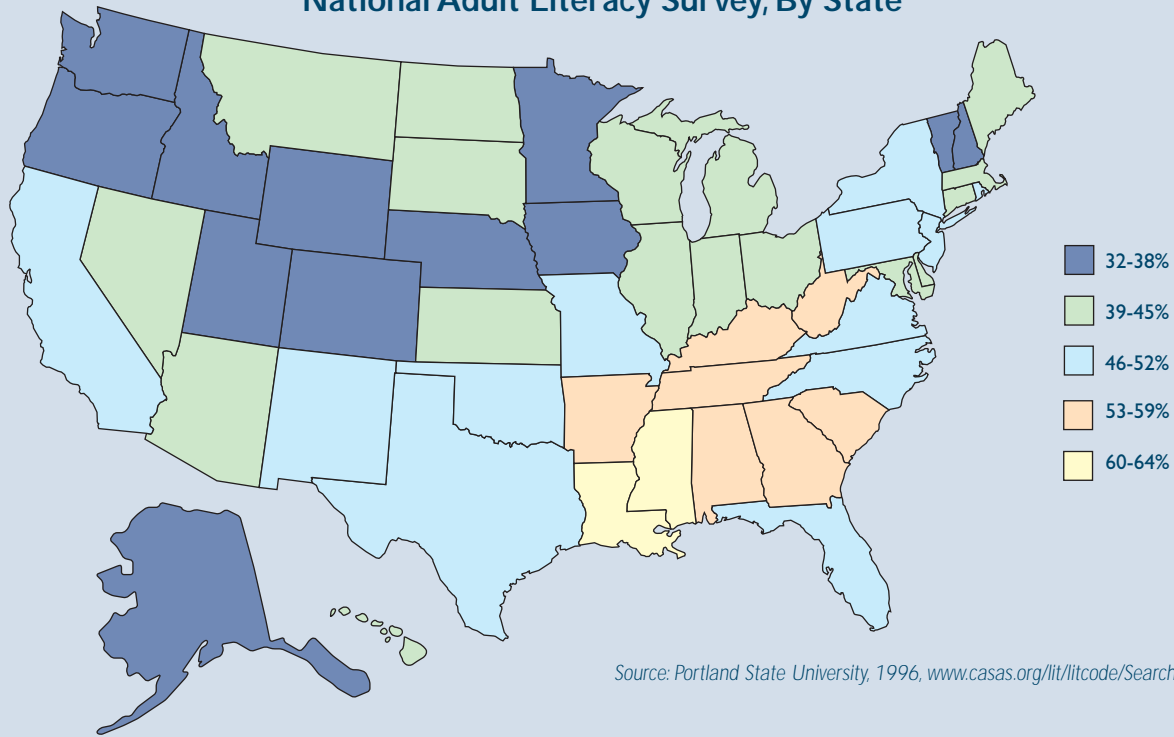
- ◆ Good health is integral to the success of adult students.
- ◆ Researchers have documented the relationship between poor health outcomes and low literacy.
- ◆ The information and skills taught are immediately relevant to the lives of adult students.
- ◆ Students in adult education classes value health information and recognize its role in improving their literacy skills.
- ◆ Adult education teachers have the training necessary to present health information to individuals with low literacy skills.
- ◆ Both healthcare and adult education benefit from working together to achieve common goals.

Source: Adapted from the Massachusetts Adult Basic Education Curriculum Framework for Health, www.doe.mass.edu/acls/frameworks/health.pdf.

By June 2000, the department had formed a Health Literacy Advisory Committee. Members included two of the premier researchers in the field, Dr. Ruth Parker and Dr. Mark Williams, both of the Emory University School of Medicine, and well-known physicians, health system administrators, and other health care professionals. This group helped design a framework for the program, setting goals, and developing relationships between the adult literacy and healthcare communities. In July 2001, Dr. DeVard-Kemp hired the state's first health literacy coordinator, Amy Jones. Jones, a nurse with many years' experience working with health education and the community, believes that hiring someone with a health background brought added expertise to the project.

For the program's initial rollout in October 2001, seven pilot sites were chosen throughout the state, in both urban and rural settings. In January 2003, five more sites were added. At the suggestion of Dr. DeVard-Kemp, the program was designed as a gateway to adult literacy – a way to attract individuals who had low literacy skills but who had not sought assistance from the adult education system. Program designers hoped that, once students were reintroduced to the classroom, they would continue to take classes and graduate from Georgia's General Educational Development (GED) program.

Figure 1. Percent of Population Scoring in the Lowest Levels on the 1992 National Adult Literacy Survey, By State



“To Your Health”

A curriculum designed specifically for the program, titled “To Your Health,” provides lesson plans and guidelines for teaching, but each site is encouraged to tailor the course to the needs of the students and the community. Classroom time ranges from a minimum of 12 hours to a maximum of 20 hours.

“The curriculum incorporates instruction on information gathering, asking appropriate and informed questions, and decision-making competency,” Lee said. “It is designed to improve adult learners’ ability to navigate the health care system, read and understand information about health, and respond accordingly. Most importantly, it encourages learners to actively participate in creating and promoting a healthy living environment.”

During the first session, the instructor administers the TOFHLA – the Test of Functional Health Literacy in Adults. This test measures each student’s health literacy by evaluating numeracy and reading comprehension skills. Using the results, the teacher is better able to plan class activities and tailor lessons to meet students’ needs. Themes covered in the curriculum include:

- ◆ Understanding the content of medical forms
- ◆ Identifying ways to pay for medical care
- ◆ Identifying health resources and services in the community
- ◆ Understanding medicine labels and prescription directions
- ◆ Effective verbal and nonverbal communication skills for health
- ◆ Understanding the influence of culture-based beliefs on health-related behaviors
- ◆ Demonstrating strategies for preventing common illnesses
- ◆ Maintaining safety at home and at work
- ◆ Understanding nutrition for good health.

The remaining weeks are spent presenting information about illnesses and prevention topics, and instructors are encouraged to

invite health care professionals into the classroom to team-teach specific subjects. At the end of the course, instructors administer the TOFHLA a second time, providing pre- and post-test scores that are used to evaluate the student’s progress and the program’s effectiveness.

Recruiting Students

Instructors at each site are responsible for recruitment and are encouraged to partner with community organizations to increase awareness of health literacy and identify individuals who would benefit from the class. To encourage participation at the two English as a Second Language (ESL) sites, instructors give students who have completed the health literacy course priority when filling openings in their adult literacy program. According to Amy Jones, “these classes are always filled to capacity because there are so many ESL students interested in speaking English and obtaining their citizenship.”



When working with the medical community, project staff found it was important for doctors to understand that the purpose was not to teach health education or to interfere with the physician-patient relationship. “Doctors want their patients to take their medicine every eight hours. Adult literacy teachers want students to know how to tell time. Using prescription drug dosing instructions to teach this skill is a win-win for everyone,” said Jones.

Efforts are currently underway to determine program outcomes by comparing pre- and post-test TOFHLA scores and by tracking the number of participants who go on to enter the Adult Literacy Program and complete Georgia's GED program. "We know that many do transition into adult basic education programs," Lee said, "and the future of the program looks good."

Figure 2. High School Completion Rates Among the Population 25 Years and Over, By State, March 2002

The map displays the following distribution of states across the four completion rate categories:

- 78-81% (Dark Blue):** California, Texas, New Mexico, Louisiana, Mississippi, Alabama, Georgia, South Carolina, North Carolina, Virginia, West Virginia, Kentucky, Tennessee, Indiana, Michigan, Ohio, Pennsylvania, Maryland, Delaware, Connecticut, Rhode Island, Massachusetts, Vermont, New Hampshire, Maine.
- 82-85% (Light Green):** Nevada, Arizona, Oklahoma, Illinois, Wisconsin, Minnesota, Iowa, Missouri, Arkansas, Louisiana, Mississippi, Alabama, Georgia, Florida, New Jersey, New York, Connecticut, Rhode Island, Massachusetts, Vermont, New Hampshire, Maine.
- 86-89% (Very Light Blue):** Washington, Oregon, Idaho, Montana, Wyoming, Colorado, Utah, Nebraska, Kansas, Oklahoma, Arkansas, Louisiana, Mississippi, Alabama, Georgia, Florida, New Jersey, New York, Connecticut, Rhode Island, Massachusetts, Vermont, New Hampshire, Maine.
- 90-93% (Orange):** Alaska, Hawaii.

Source: U.S. Census Bureau

California Literacy

California Literacy, the oldest and largest statewide adult volunteer literacy organization in the United States, hopes to tackle the issue of health literacy through its California Health Literacy Initiative. This project seeks to improve health literacy among at-risk populations and increase awareness of the effect low health literacy has on health among health care providers and educators.

Components of the initiative include:

- ◆ Elevate the status of health literacy to make it a definite priority for major health care organizations.
- ◆ Create a clearinghouse of health literacy information and resources.
- ◆ Build awareness of the problems associated with low health literacy among health care providers.
- ◆ Participate in the development of a baseline standard of accessibility that will help communities evaluate whether the systems they have in place are suitable for someone with low health literacy.

For more information, visit www.caliteracy.org/cahealthliteracyinitiative.html



a state where adult education was under the purview of the Department of Education. “What is important is the partnership between health care and adult education. Together, they are unstoppable,” said Lee.

Conclusion

By using health materials to teach literacy, Georgia has discovered a way to meet both the adult learners’ need for real-world skills and the health care system’s need for individuals who are able to successfully navigate the system, make sound health care decisions and follow a doctor’s instructions. Georgia’s Health Literacy Pilot Project may be the first of its kind, but if it proves successful in increasing health literacy among adults with poor reading comprehension and numeracy skills, it will hopefully not be the last.

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Lessons Learned

Although the program is still relatively new, the state has already learned a lot about the community’s perception of health literacy. “Health care is ready to embrace health literacy,” Lee said, citing support from the Georgia Chapter of the American Medical Association, the Georgia Pharmacy Association and others.

In reflecting on how other states may replicate Georgia’s pilot project, Lee noted that a key factor would be a state’s adult education infrastructure – including where the department is housed, the funding and resources available and support from state leadership. Having the Office of Adult Literacy housed in the state’s Department of Technical and Adult Education may have been a plus for Georgia, but it doesn’t necessarily mean that the project couldn’t be piloted in

Additional Resources

- ◆ “Health & Literacy.” National Institute for Literacy (www.worlded.org/us/health/lincs/).
- ◆ “Health Literacy and the Adult ESL Learner.” *ERIC Digest* (www.cal.org/ncle/digests/healthlitQA.htm).
- ◆ “Health Literacy beyond Basic Skills.” *ERIC Digest* (<http://ericacve.org/docs/dig245.pdf>).
- ◆ “Literacy, Health, and Health Literacy: State Policy Considerations” *Focus on Basics* (www.gse.harvard.edu/~ncsall/fob/2002/hohn.html).
- ◆ “Picture Stories for Adult ESL Health Literacy.” National Center for ESL Literacy Education (<http://www.cal.org/ncle/health/>).
- ◆ *Promoting Health Literacy: A Report of the Institute on Family and Neighborhood Life at Clemson University* (<http://scl.clemson.edu/assets/pdf/HealthLi.pdf>).



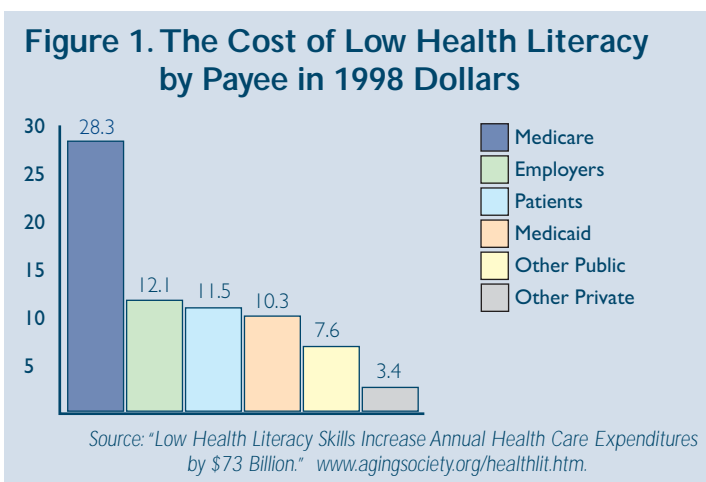


Fact Sheet

Health literacy – the ability to read, understand, and act appropriately on health care information – directly affects an individual’s ability to access services and successfully communicate with his or her health care provider. Low health literacy results in a fundamental disconnect between the patient and the health care system. This rift inevitably leads to a lack of trust and honesty, poorer quality care, errors and omissions, and higher costs.

What is the impact of low health literacy?

Inadequate health literacy costs the U.S. health care system an estimated \$30 billion to \$73 billion annually, according to a 1998 study done by the National Academy on an Aging Society. When broken down to expenditures by payer, this means that Medicaid spends as much as \$10 billion annually on low health literacy – almost as much as Medicaid spent on prescription drugs and more than one-and-a-half times the amount it spent on physician services in 1998 (Figure 1).



Low health literacy also affects an individual’s ability to access appropriate care. Complicated forms and procedures, rules about in-network and out-of-network providers, tiered co-payment structures, as well as other aspects of modern health care act as barriers to someone with low health literacy. A 1996 survey of 400 Medicaid managed care beneficiaries in New York found that more than 30 percent did not know managed care limited them to a specific network of providers, 60 percent did not know a referral was required to see a specialist, and 80 percent did not know use of the emergency room was limited.

Quality of care is also compromised. A more informed and involved health care consumer knows what questions to ask about a test or procedure and feels empowered to prevent medical errors

before they happen. Without this knowledge, many agree to care without really understanding what is happening. A study published in the *Journal of the American Medical Association* found that of the 3,442 clinical decisions made during 1,057 encounters between a physician and a patient, only 9 percent met the criteria for informed consent.

Who is affected by low health literacy?

There is no national measure of health literacy. Data from the 1992 National Adult Literacy Survey show that more than 90 million adults in the United States – almost half the adult population – have low or marginal literacy skills. Studies of specific patient populations also point to groups vulnerable for low health literacy. However, given today’s complicated health care system, no one is immune from having difficulty accessing appropriate care, understanding health information and making informed health care decisions.

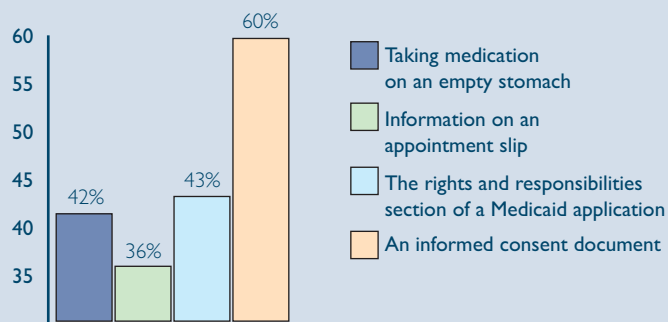
- ◆ **Low-Income:** Individuals eligible to participate in Medicaid, SCHIP, WIC, maternal/child health programs and other public programs based on income are often at-risk. The 1992 National Adult Literacy Survey revealed that 43 percent of individuals with low literacy lived in poverty and 70 percent had either no job or only a part-time job.
- ◆ **Seniors:** A survey of Medicare managed care enrollees in four cities found that more than a third of English-speaking and more than half of Spanish-speaking enrollees had inadequate or marginal health literacy. The study also found that reading skills decreased significantly with age.
- ◆ **Chronically Ill:** In two 1998 studies of people with diabetes, high blood pressure and asthma, researchers found that literacy skills were the strongest link between patients and their knowledge of their disease, even when other factors such as education were taken into consideration.
- ◆ **Non-English Speakers:** According to *The Commonwealth Fund 2001 Health Care Quality Survey*, less than half of those non-English speakers claiming to need a translator during office visits always or usually had access to one. In the absence of an interpreter, many patients are forced to rely on family members to aid in doctor-patient communication.

Why is health literacy important?

A number of trends in the American healthcare system highlight the importance of health literacy, especially among beneficiaries of public health insurance programs:

- ◆ **Rising Health Care Costs:** Because of the increased costs associated with low health literacy, providing appropriate information or increasing skills among beneficiaries will

Figure 2. Percent of Patients at Two Public Hospitals Who Did Not Understand Basic Health Information



Source: Williams, M., Parker, R., Baker, D., et al. "Inadequate Functional Health Literacy Among Patients at Two Public Hospitals." *JAMA*, 1995, v274n21: 1677-1682.

undoubtedly lead to increased efficiencies and decreased expenditures.

- ◆ **Managed Care:** HMOs, PPOs, and other forms of managed care insurance plans assume that patients will play an active role in managing their health. Without the tools and skills needed to access and navigate these complex systems, however, individuals with low health literacy will be unable to take on these responsibilities.
- ◆ **Innovations in Treatment:** Although recent medical advances have done much to improve the quality of life, the increasing complexity of treatments affects a person's ability to make informed health care decisions. Individuals with low health literacy face significant challenges in following dosage instructions, preventing medical errors, and providing informed consent.
- ◆ **An Aging Population:** Studies have shown that aging is associated with decreased health literacy. Efforts to control costs and improve the quality of care for seniors must include strategies for improving seniors' ability to understand and act on health information.
- ◆ **Cultural and Linguistic Diversity:** As the U.S. population becomes more diverse, differences in language and cultural beliefs will act as a barrier to successful communication between physician and patient, health plan and member.

CSG's National Survey on Health Literacy Initiatives

During the spring of 2002, The Council of State Governments, with the support of Pfizer, Inc., conducted a national survey to find out what states were doing to improve health literacy or to make the health care system easier to navigate. CSG's *National Survey on Health Literacy Initiatives* was sent to governors' offices, departments of health, Medicaid and SCHIP offices, departments of education, and offices of adult literacy.

What are states doing to address health literacy?

Although few states that have addressed health literacy in a comprehensive, multifaceted manner, several initiatives show states have a role in improving health literacy.

- ◆ The Louisiana Legislature passed legislation to create an Interagency Task Force on Health Literacy to study health literacy and develop recommendations for improving health literacy in Louisiana. Members will include representatives from health

and human service agencies, consumer and family advocacy groups, and health care service providers.

- ◆ Georgia's Department of Adult and Technical Information has hired a Health Literacy Coordinator to oversee the implementation of its Health Literacy Pilot Project. Through the program, adult learners are taught needed skills using health information.
- ◆ Virginia's Center for Primary Care and Rural Health established a Health Literacy Network to promote the use of plain language and to offer resources to health care providers, agency staff and others wanting to assist specific populations access care. In 1999, the Center sponsored a health literacy conference for national, state and local health care programs.
- ◆ The state of Alaska produced "Healthy Reading Kits" for grades two through eight. The texts referenced in the kit have strong health content, and the teacher's manual that accompanies the kit helps educators tie the books to Alaska's reading standards.
- ◆ California approved its *Health Framework for California's Public Schools, Kindergarten Through Grade Twelve*, a tool to aid health education curriculum development at the local level and to promote collaborations between schools, parents and the community.
- ◆ Massachusetts' medical assistance programs have been at the forefront of providing multilingual assistance, videos in multiple languages and training staff to convey health care information in a way that is easy to understand. Massachusetts also has an Adult Basic Education Health Curriculum Framework for use in adult literacy classes.
- ◆ Alabama's Medicaid agency has done extensive pilot testing of materials for enrollees. Through this work, the agency has learned that easy-to-read materials are preferred, even by those with proficient reading skills.

What can policy-makers do?

In tackling this issue, state policy-makers can:

- ◆ Hold hearings or convening conferences about health literacy.
- ◆ Establish a task force or advisory group to provide recommendations for state action.
- ◆ Simplify enrollment forms and procedures for accessing services through state programs.
- ◆ Promote the use of plain language by rewriting and reformatting written materials to increase their accessibility.
- ◆ Require documents be written at a sixth-grade reading level or below.
- ◆ Incorporate graphics and white space, and increase font sizes to make materials more user-friendly.
- ◆ Translate relevant information – either written or verbal – into an individual's native language. When translating documents, ensure that the message isn't lost in translation and is relevant to the reader.
- ◆ Train agency staff and health care providers in effective communication strategies for individuals with low health literacy.
- ◆ Incorporate health materials and health education in the classroom at all levels – K-12 and adult literacy classes.

— This publication was prepared by Jenny Sewell, health policy analyst, for the Council of State Governments. For more information about health literacy at CSG, please contact her at (859) 244-8154 or jsewell@csg.org. The Council of State Governments would like to thank Pfizer, Inc., for its support in creating the Health Literacy Tool Kit.



Louisiana House Bill No. 2019

Regular Session, 2003

Creates the Interagency Task Force on Health Literacy

A. Legislative intent

The legislature recognizes that the Louisiana State University Health Sciences Center in Shreveport has conducted seminal research in health literacy and is nationally known for its work. This effort has been led by the Department of Medicine and Pediatrics with participation of faculty and staff from other departments. The legislature wishes to create a statewide task force to address health literacy in Louisiana in order to address health care access, reduce unnecessary health spending, and improve health outcomes.

B. As used in this Section:

(1) "Chancellor" means the chancellor of the Louisiana State University Health Sciences Center in Shreveport.

(2) "Health literacy" means an individual's ability to read, understand, and act appropriately on health care information.

(3) "Task force" means the Interagency Task Force on Health Literacy.

C. Not later than December 1, 2003, the chancellor shall establish the task force to assist the health and human service agencies of this state in studying health literacy and developing recommendations for improving health literacy in this state.

D. Membership

(1) The chancellor shall appoint a member of the Louisiana State University Health Sciences Center-Shreveport faculty to chair the task force.

(2) The following representatives shall be invited to serve on the task force:

(a) Three representatives from state hospitals to be selected by the vice chancellor of the Health Care Services Division, Louisiana State University Health Sciences Center-New Orleans.

(b) A representative from the office of public health, maternal and child health program.

(c) A representative from the Louisiana Primary Care Association.

(d) A representative from the Louisiana Public Health Institute.

(e) A representative from the Louisiana State Medical Society.

(f) A representative from the Louisiana Chapter, American Academy of Pediatrics.

(g) A representative from the Governor's Office of Elderly Affairs.

(h) A representative from the eligibility section of the Medicaid Program.

(i) A representative from the School of Pharmacy at the University of Louisiana at Monroe.

(j) A representative from the area health education centers.

(k) A representative from the Southeastern Louisiana University Nursing School.

(l) A representative from the Developmental Disabilities Council.

(m) A representative from the Louisiana State University Cooperative Extension.

(n) A representative from the Southern University Cooperative Extension.

(o) A representative of the health insurance industry.

- (p) A representative from the Louisiana Chapter of the National Medical Association.
- (q) A representative from the Louisiana Minority Health Commission.
- (r) A representative from Xavier School of Pharmacy.
- (3) The task force shall meet at the call of the presiding officer.
- (4) No member of the task force shall receive compensation for serving on the task force.
- (5) The task force may consult with and invite participation from other groups, organizations, and agencies as may be needed.

E. The Louisiana State University Health Sciences Center-Shreveport shall provide the staff necessary to assist the task force in performing its duties.

F. The task force shall study and evaluate the health literacy of the residents of this state. The task force shall:

- (1) Examine the ability of residents to access available health services and communicate with health care providers.
- (2) Identify barriers that prevent residents with low health literacy from receiving health care.
- (3) Identify groups at risk for low health literacy.
- (4) Examine whether providing appropriate health information to and increasing the health literacy of the beneficiaries of public health services would increase the efficiency of health care providers and decrease expenditures.
- (5) Examine the impact on health literacy of:
 - (a) Rising health care costs.
 - (b) Increasingly complex health treatments.
 - (c) An individual's age.
 - (d) Cultural and linguistic diversity.

G. Not later than December 15, 2005, the task force shall report to the legislature on its findings under Subsection F and make recommendations to the legislature on strategies for:

- (1) Improving the health literacy of the residents of this state.
- (2) Promoting the use of plain language by health care providers.
- (3) Simplifying the enrollment forms and procedures for accessing health insurance plans serving individuals in groups identified as at risk for low health literacy.
- (4) Developing resources for health care providers and residents of this state to increase health literacy.
- (5) Developing programs to aid the residents of this state in understanding health care information.
- (6) Developing educational curricula to increase health literacy.
- (7) Developing easy-to-understand print and electronic information on health issues.
- (8) Funding the recommendations of the task force.

H. The task force shall terminate on September 1, 2006.

